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Participation and Activity Limitation Survey 2006: Families of Children with Disabilities in Canada

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.	not available for any reference period
..	not available for a specific reference period
...	not applicable
0	true zero or a value rounded to zero
0^s	value rounded to 0 (zero) where there is a meaningful distinction between true zero and the value that was rounded
^{p}	preliminary
^{r}	revised
x	suppressed to meet the confidentiality requirements of the *Statistics Act*
^{E}	use with caution
F	too unreliable to be published

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Introduction

Over the last few years, increased attention has been paid to the issue of disability. With rising disability rates and more children being diagnosed with activity limiting conditions, an increasing number of Canadian parents are coping with the challenges that arise from caring for a child with disabilities. These challenges are diverse in nature, and can affect every aspect of family life.

Previous research has found that families of children with disabilities experience higher levels of stress, illness, and marital strain compared to families without children with disabilities (Dowling and Dolan, 2001). Further, as children with disabilities may require a greater amount of their parent's time, families face the additional challenge of having to balance caregiver responsibilities with other life commitments such as work, leisure, and personal relationships.

Using data from the 2006 Participation and Activity Limitation Survey (PALS), the following report examines how caring for a child with a disability impacts the family unit, and more specifically, the parents who care for them. This report explores issues such as household income, health and stress, employment and finances, marital relationships, and childcare arrangements. Further, this report explores the availability of financial and care giving supports as well as issues relating to transportation.

Text box 1 An overview of the Participation and Activity Limitation Survey

The Participation and Activity Limitation Survey (PALS) is a post-censal survey that was conducted shortly after the 2001 and 2006 Census. The PALS collects information about persons with disabilities whose everyday activities are limited because of a health-related condition or problem. The most recent survey took place between November 2006 and February 2007. The PALS is funded by Human Resources and Social Development Canada (HRSDC).

For the purpose of PALS, persons with disabilities or activity limitations are those who reported difficulties with daily living activities, or who indicated that a physical or mental condition, or health problem reduced the kind or amount of activities they could do. The respondents' answers to the disability questions represent their perception of the situation and are therefore subjective.

Throughout this paper, persons with a disability or activity limitation are used interchangeably and are referring to the same population of people.

It is important to note that this report is based on child-level data. This means that all numbers (or percentages) in fact represent the number (or percentage) of children with disabilities whose responding parent gave a certain response to the survey. For the purpose of this report, the expression "number (or percentage) of parents of children with disabilities" is used throughout the text. Also, it is important to note that the child is the respondent, and parents are answering on their behalf. Therefore, it cannot be inferred from this report that the findings are representative of all parents of children with disabilities. Furthermore, what we refer to as "parent" could have been whoever served as the child's guardian during the time of data collection.

For more information, please refer to the Participation and Activity Limitation Survey 2006: Technical and Methodological Report (89-628-X).

The prevalence of disability among children in Canada

In 2006, 3.7% of Canadian children under the age of 15 were reported as having one or more disabilities (table 1). A higher rate of disability was reported for boys (4.6%) compared to girls (2.7%). Furthermore, disability rates increased for each age category. Children aged 4 years or younger had a disability rate of 1.7%, those aged 5 to 9 had a disability rate of 4.2%, and those aged 10 to 14 had a rate of 4.9%.

Table 1
Disability rates for children under the age of 15, by sex and age groups, Canada, 2006

Age group	Child disability rates	Disability rates among boys	Disability rates among girls
	number		
0 to 14	202,350	129,210	73,140
0 to 4	27,540	17,770	9,770
5 to 9	74,580	48,290	26,300
10 to 14	100,230	63,150	37,070
	percent		
0 to 14	3.7	4.6	2.7
0 to 4	1.7	2.1	1.2
5 to 9	4.2	5.3	3.0
10 to 14	4.9	6.0	3.7

Note: Includes Yukon, Northwest Territories and Nunavut.
The sum of the values in the category may differ from the total due to rounding.
Source: Statistics Canada, *Participation and Activity Limitation Survey, 2006*

Text box 2 Types of disability among children

The Participation and Activity Limitation Survey (PALS) questions allow the identification of the following types of disabilities among children:

Agility:** Difficulty bending, dressing and undressing oneself, getting into or out of bed, cutting own toenails, using fingers to grasp or handling objects, reaching in any direction, or cutting own food.

Chronic condition*: Limit in the amount or kind of activities that one can do due to the presence of one or more chronic health conditions that have lasted or are expected to last six months or more and that have been diagnosed by a health professional.

Communication:** Difficulty speaking and / or being understood.

Developmental delay*:** Cognitive limitations due to the presence of a developmental disability or disorder, such as Down syndrome, autism or mental impairment caused by a lack of oxygen at birth.

Hearing*: Difficulty hearing what is being said in a conversation with one other person, in a conversation with three or more persons, or in a telephone conversation.

Learning:** Difficulty learning because of a condition, such as attention problems, hyperactivity or dyslexia.

Text box 2 Types of disability among children (concluded)

Mobility:** Difficulty walking half a kilometre or up and down a flight of stairs, about 12 steps without resting, moving from one room to another, carrying an object of 5 kg (10 pounds) for 10 metres (30 feet) or standing for long periods.

Other*: The Participation and Activity Limitation Survey (PALS) also collected information on other needs for assistive devices that were not exclusive to a specific disability type. Respondents from any disability type could report any other assistive device needs or usage in this section.

Psychological**: Limit in the amount or kind of activities that one can do due to the presence of an emotional, psychological or behavioural condition.

Seeing*: Difficulty seeing ordinary newsprint or clearly seeing someone's face from 4 meters away (12 feet).

* Applicable to all children under 15.
** Applicable to children aged 5 to 14.
*** Applicable to children under 5.

For more information, please refer to the Participation and Activity Limitation Survey 2006: Technical and Methodological Report (89-628-X).

Impact of child's disability on the family

Parental health and life satisfaction

When examining the state of health for parents who had a child with a disability, over six in ten (64.8%) parents reported having health that ranged from good to excellent. Moreover, over eight in ten (81.7%) considered their life satisfaction to be good to excellent. As severity increased, twice as many parents reported being in fair or poor health (22.8%) and / or having fair or poor life satisfaction (24.1%). This is in contrast to parents of children with milder disabilities with rates of 11.9% and 13.2%.

Text box 3 Severity of disability

An index measuring the severity of the disability was constructed based on the answers to the survey questions. Points were given according to the intensity and the frequency of the activity limitations reported by the respondent. A single score was computed for each type of disability. Each score was then standardized in order to have a value between 0 and 1. The final score is the average of the scores for each type of disability.

Since the survey questions differ depending on the age of the respondent, a different scale was constructed for adults, for children under 5 and for children aged 5 to 14. Each scale was then divided into different severity levels. The scale for children aged 5 to 14 was divided into four groups (that is, mild, moderate, severe and very severe).

The Participation and Activity Limitation Survey (PALS) severity scale was derived using disability concepts from the World Health Organization.

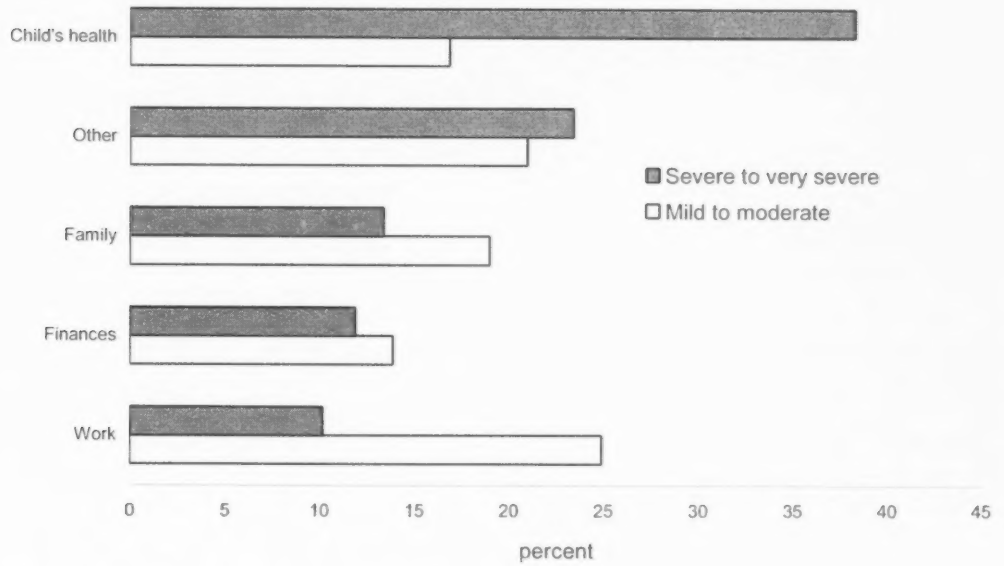
For more information on this scale, please refer to the Participation and Activity Limitation Survey 2006: Technical and Methodological Report (89-628-X).

Child's health condition main source of stress

Stress is a fact of daily life and is the result of both the good and bad things that happen. Income, work, marriage and family difficulties can add stress to a person's life. However, when parents have a child with a disability combined with other sources of stress, it may add additional strain on the family.

Almost half of parents (45.5%) said that their daily stress ranged from quite a bit stressful to extremely stressful, while 39.8% said that most of their days were a bit stressful. A quarter of those parents reported their child's health condition as the main source of stress (26.5%). The severity of the child's disability had an impact on whether a parent cited their child's health as their main source of stress in daily life. More specifically, 16.8% of parents of children with a mild to moderate disability reported that their main source of stress was their child's health, whereas more than twice as many (38.3%) parents of children with a severe to very severe disability stated the same (chart 1).

Chart 1
Main source of stress for parents of children with disabilities, by severity of child's disability, Canada, 2006



Source: Statistics Canada, *Participation and Activity Limitation Survey, 2006*

Finding time between caring for the child and other responsibilities a source of stress

Attempting to balance responsibilities related to the child's condition and daily life may contribute to anxiety for the parents. Over six in ten (61.4%) parents reported sometimes or always having feelings of stress between the responsibilities of caring for their child with a disability and other obligations such as work. This was most pronounced when looking at the severity of the disability. Nearly half (46.2%) of parents of children with a mild to moderate disability reported sometimes or always having feelings of stress between the responsibilities outlined above. This rate nearly doubled to 81.7% for parents of children with severe to very severe disabilities.

Parents with children with severe disabilities felt they should be doing more for their child

Parents of children with severe to very severe disabilities were less content with the help they provided for their child compared to parents of children with mild to moderate disabilities. For instance, 56.6% of parents with children with mild to moderate disabilities sometimes or always felt they should be doing more for their child. This was compared to almost four in five parents of children with more severe disabilities (78.5%) who reported similar feelings.

Parents reduced the number of hours they work

One area that is affected when parents have a child with an activity limitation is that of employment. Flexible work schedules or options to telework are helpful for parents who need to care for their child and at the same time continue working.

Parents listed a variety of areas in which their employment was influenced due to the child's activity limitation. The largest impact reported related to hours worked. In particular, over one-third (38.4%) of parents stated working fewer hours, and an additional one-third (36.5%) of parents adjusted their work hours due to their child's disability. Parents of children with severe to very severe disabilities reported higher rates of impact on employment than did parents of children with less severe disabilities (table 2).

Table 2
Employment impact for parents of children with disabilities, by severity, Canada, 2006

Employment Impact	Severity		
	Total	Mild to moderate	Severe to very severe
	percent		
Not taken a job	**26.4**	16.4	39.8
Quit working	**21.6**	13.2	32.9
Changed work hours	**36.5**	26.9	49.4
Turned down promotion	**19.7**	10.5	31.9
Worked fewer hours	**38.4**	29.1	50.8

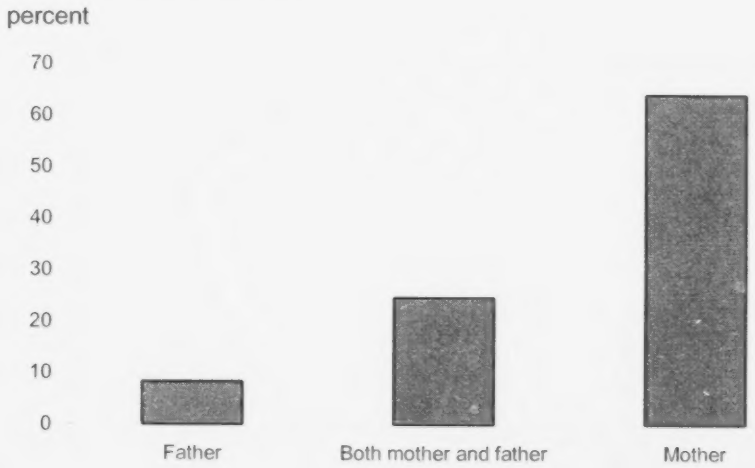
Source: Statistics Canada, *Participation and Activity Limitation Survey, 2006*

Mothers' employment most affected by child's disability[1]

Over six in ten mothers were the main person to be impacted regarding employment modifications (64.1%), compared to less than one in ten fathers (8.3%; chart 2). However, almost one quarter of both mothers and fathers shared the employment adjustments equally.

In cases where the mother's employment was reported as being the one most affected by the child's disability nearly two-thirds of mothers reported working fewer hours (63.3%), while half of mothers reported having to adjust their work hours (55.6%).

Chart 2
Proportions of caregivers of children with disabilities whose employment is most impacted, Canada, 2006



Source: Statistics Canada, *Participation and Activity Limitation Survey, 2006*

Disability and financial well being

In 2005, the median annual household income for families with children with disabilities was $59,980 and the average was $68,940. A correlation was found between a family's likelihood of falling below the Low-Income Cut-Off (LICO) and whether or not a child with a disability was present in the household. In 2005, nearly one in five (19.1%) children with an activity limitation lived in a household that fell below the LICO compared to 13.4% of households with a non-disabled child.

Text box 4 Low-income cut-off (LICO)

Low-income cut-off (LICO) is the income below which most Canadians spend at least 20 percentage-points more than the average on food, shelter and clothing.

1. It is important to note that information relating to the employment of lone parent families was not available for this report. The question on employment adjustments asks whether modifications had ever been made to accommodate the child's disability, however it did not ask the respondent when that modification had been made. Although the parent's current marital status can be identified, there is no way of knowing what their marital status was at the time of the employment adjustment.

Over eight in ten families (81.8%) reported no financial problems due to the child's condition or health problem within the previous 12 months. The story changes however when severity of the disability is taken into account. Approximately 30.3% of families of children with a severe to very severe disability reported financial difficulties; a rate more than three times higher than families of children with mild to moderate disabilities at 8.6%. This financial strain may be associated to the extra cost related to special accommodations for the child's condition. The cost of equipment and services rise as severity of the disability increases.

Effects on parents' personal time

Children often create a busy schedule for their parents. Between school, homework and extracurricular activities, it leaves little time for parents to have any personal space. Finding personal time may be more difficult for parents who have a child with an activity limitation that requires additional care and attention.

Half (51.6%) of parents reported sometimes or always feeling that they had less personal time due to the responsibilities associated with the child's condition. These feelings were highly contingent upon the severity of the child's disability. Parents of children with a mild to moderate disability were less than half as likely than parents of children with more severe disabilities to report sometimes or always feeling that they had less personal time with rates of 34.9% and 73.9% respectively.

Child's condition impacts current parental relationship

The strain of having children in the family may be made more complex when one of the children has a disability. This may add additional pressure on the relationship of the mother and father.

When asked about current relationships 76.7% of parents indicated that they were married or living common-law. Nearly half (49.9%) of parents reported that their child's condition had little or no affect on the marital or common-law relationship, while nearly one in five (18.1%) reported becoming closer with their partner due to the child's condition. However, 30.9% reported that the child's disability caused problems in the relationship.

Parents of children with a severe to very severe disability were more than twice as likely than parents of children with less severe disabilities to report that some problems in their relationship were related to their child's condition (43.5% and 21.9%; table 3).

Table 3
Impact of child's disability on current parental relationship, by severity, Canada, 2006

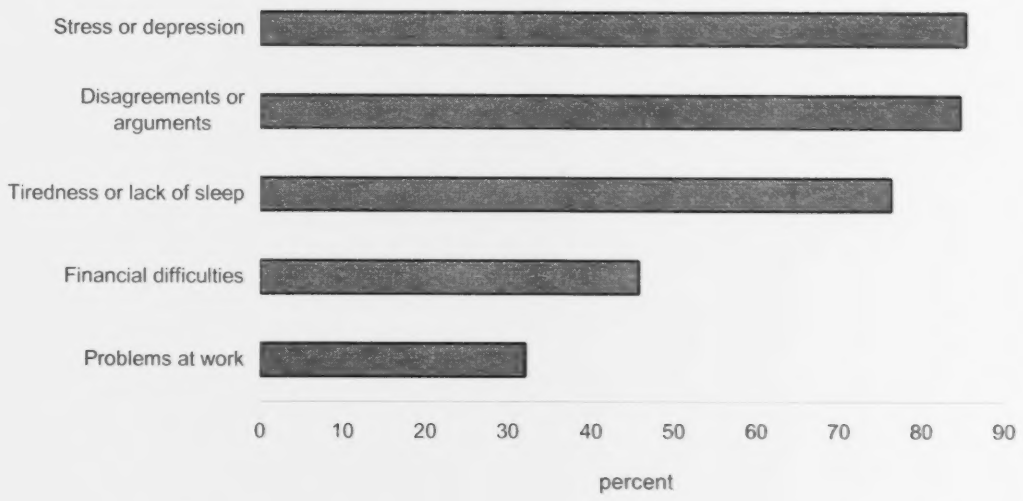
Impact on Current Relationship	Severity		
	Total	Mild to moderate	Severe to very severe
	percent		
Brought couple closer together	**18.1**	15.8	21.3
Little or no effect	**49.9**	61.5	33.7
Caused problems	**30.9**	21.9	43.5

Source: Statistics Canada, *Participation and Activity Limitation Survey, 2006*

Reported problems in parents' relationship

In those cases where the child's condition did present some difficulties in the relationship between the mother and father, there were a variety of issues that arose. Stress and depression and disagreements and arguments were the largest problems reported by parents at 85.4% and 84.7%, followed by tiredness or lack of sleep at 76.3%, financial problems at 45.8%, and problems at work at 32.1% (chart 3).

Chart 3
Type of marital problems related to child's disability on current parental relationship, Canada, 2006



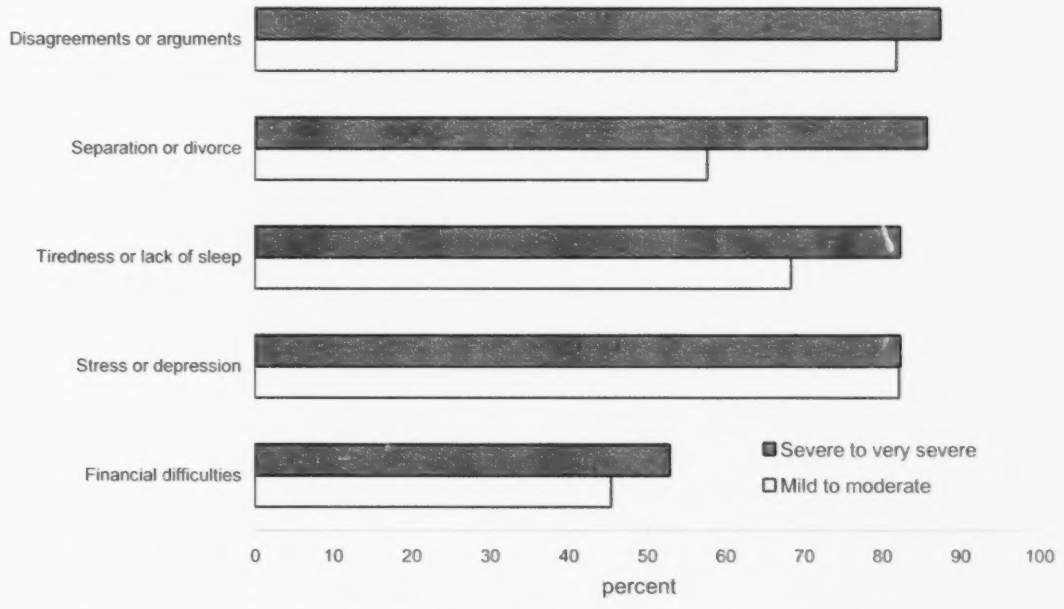
Source: Statistics Canada, *Participation and Activity Limitation Survey, 2006*

Separation and divorce

Six in ten parents (60.0%) reported being in a previous relationship since the child's birth. Of this, over four in ten parents (42.2%) stated that the child's condition had an impact on that previous relationship. Where a child's disability was mild or moderate, 28.7% of parents reported that their previous relationship had been affected by the child's disability. This rate nearly doubled for parents whose children had a more severe disability (56.6%).

There were many different ways in which the child's condition affected the former relationship. Most noticeable was that 85.6% of parents said that their child's condition caused disagreements and arguments in the relationship while, over three in four (76.0%) parents reported that their child's disability led to their separation or divorce (chart 4). A lower proportion of relationships where the child had a mild or moderate limitation (57.7%) ended in separation or divorce than relationships where the child had a more severe disability (85.8%).

Chart 4
Type of marital problems related to child's disability on previous parental relationship, by severity, Canada, 2006



Source: Statistics Canada, *Participation and Activity Limitation Survey, 2006*

Types and sources of help for parents of children with disabilities

When a family has a child with a disability, help from others may ease some of the pressure that parents may experience. Nearly one fifth of parents (18.6%) reported having assistance from others, allowing them to have some personal time. Other areas in which parents received help included tending to other family responsibilities (15.0%) and household chores and meal preparation (7.0%). There were no significant differences between lone parents and parents in relationships in regards to help received.

The help parents received came from a variety of sources. Over half of the assistance (56.5%) came from family members living outside of the family home. This was followed by help from government organizations or agencies at 37.2%, friends or neighbours at 35.0%, and family living in the family home at 33.8%.

Parents of children with a mild to moderate disability were more likely to obtain help from family members living outside of the family home (69.5%) than were parents of children with more severe disabilities (49.8%). Parents of children with a more severe disability were more likely to obtain assistance from government (46.0%) and private organizations and agencies (19.6%).

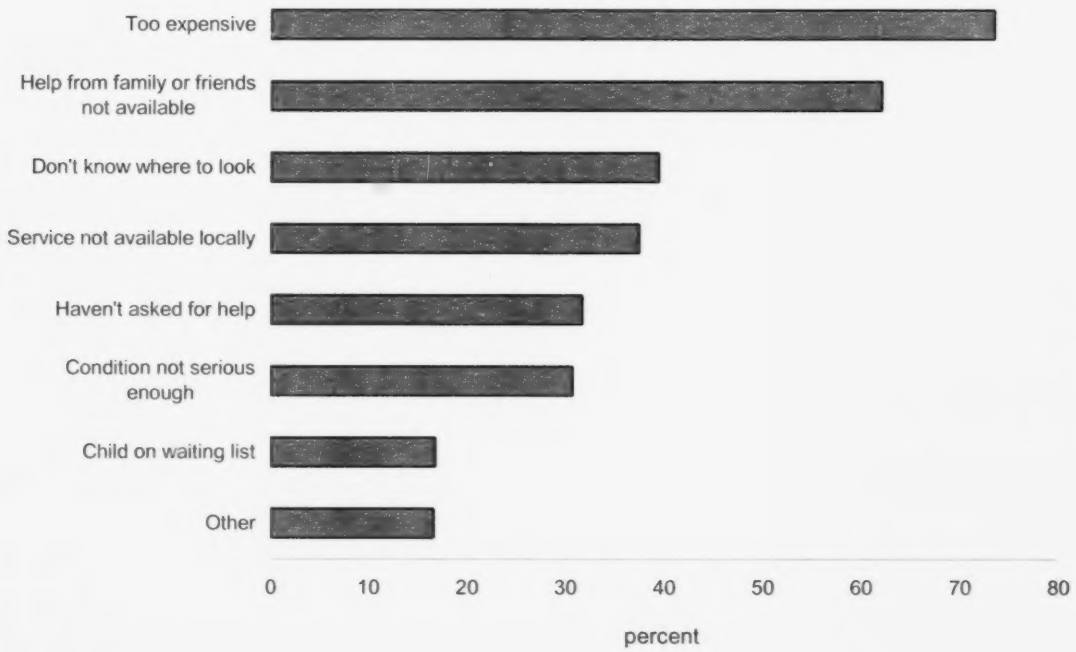
Many parents expressed a need for additional aid to allow them to have more personal time. Parents of children with severe to very severe disabilities were more likely to report needing additional help to have more time for personal activities than were parents of children with milder disabilities (29.7% versus 10.7%). Similarly, lone parents were more likely than parents in a relationship to report needing help to gain more personal time (30.7% versus 20.2%).

Cost of obtaining help

There were many reasons why extra help to parents was not realized. The overwhelming response given by parents, regardless of marital status, was the cost. Nearly three quarters (73.5%) of parents reported that the extra help was too expensive. When help comes from family members or friends, the assistance is usually free with no cost to the family. However, in other cases, there is a cost associated with help provided to the family. Over one third (36.7%) of parents reported having out-of-pocket expenses for the assistance that they had received. In 42.3% of cases, they reported paying from $200 to $1,000 for these expenses in the past 12 months, and, in 41.2% of cases, they paid over $1,000 in the past 12 months.

Many parents faced numerous barriers in obtaining adequate help. These barriers included cost, lack of local resources, and a lack of information about available services. For parents of a child with a disability, it may be difficult to locate additional help if one does not know where such resources can be located. Fewer than four in ten (37.5%) parents reported that special services were not available locally, while 39.5% of parents reported not knowing where to go to find help (chart 5).

Chart 5
Parents' reasons for difficulty in obtaining help, Canada, 2006



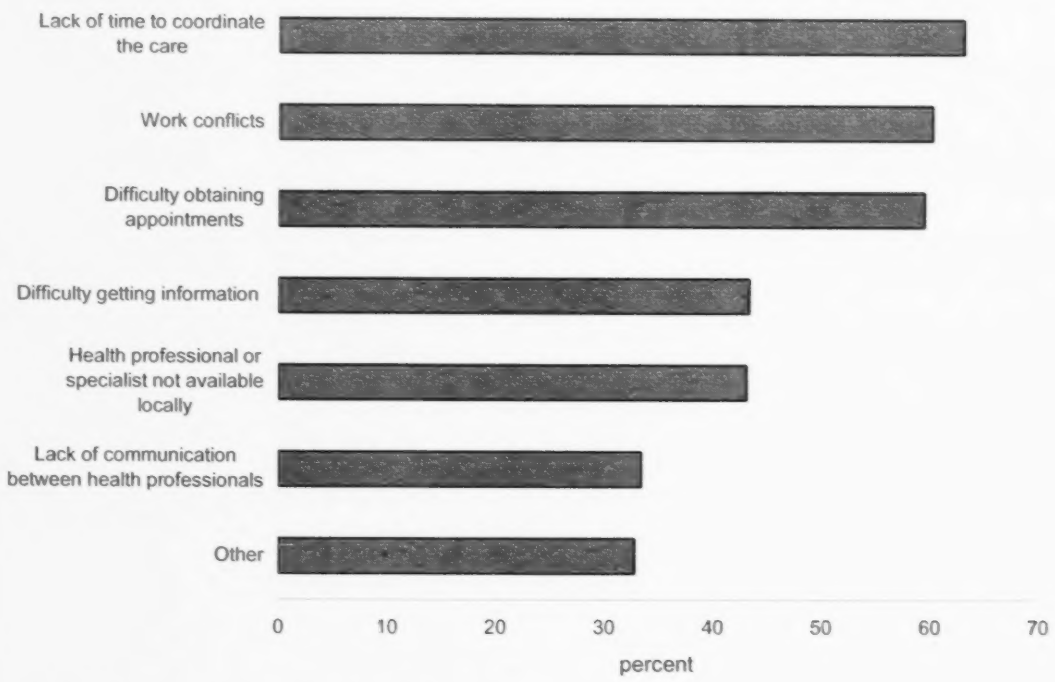
Source: Statistics Canada, *Participation and Activity Limitation Survey, 2006*

Finding and coordinating medical care poses some difficulty

When parents have a child with an activity limitation, finding and coordinating appropriate assistance is not always easy. This is especially true for parents who have a child who has recently been diagnosed with a condition. Doctors or educational staff may be able to provide some information on this subject but often the parents must conduct their own research to find the necessary resources for their child and for themselves. In 2006, over four in five parents reported having little or no difficulty in coordinating medical care for their child with a disability. This care includes such things as making appointments and phoning or visiting health professionals and specialists.

Of the 19.3% of parents who reported experiencing difficulty in coordinating care, almost two in three stated lack of time to coordinate care (63.1%) and work conflicts (60.2%) as the main obstacles (chart 6).

Chart 6
Difficulty for parents in coordinating care for their children with disabilities, Canada, 2006



Source: Statistics Canada, *Participation and Activity Limitation Survey, 2006*

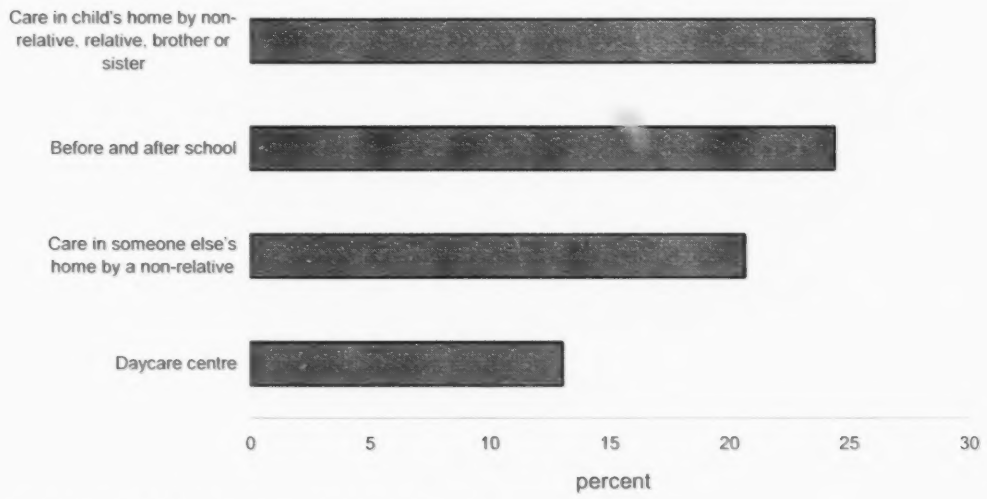
Childcare for Children with Disabilities

Many Canadian families with young children make use of childcare services. There are certain attributes that the chosen facility must have in order to meet the family's needs. Location of the best childcare for a child is made more complex when it is a child with an activity limitation. There are more specific requirements that a childcare facility must be able to address in order to accommodate the child's special needs.

In 2006, close to one third (28.9%) of parents who had a child with an activity limitation used some form of child care. Parents who were married or in a relationship were just as likely as lone parents to report using child care. The severity of the child's disability had an influence on whether or not parents made use of one of the programs. More specifically, slightly over one quarter (25.2%) of parents with children with mild to moderate disabilities used child care, compared to 34.3% for those with children with more severe disabilities.

Commonly reported child care arrangements included that of before and after school programs, with nearly one quarter (24.4%) of parents making use of such a program. In addition, one child in five (20.7%) was cared for by a non-relative in someone else's home (chart 7).

Chart 7
Main child care arrangement for children with a disability, Canada, 2006



Source: Statistics Canada, *Participation and Activity Limitation Survey, 2006*

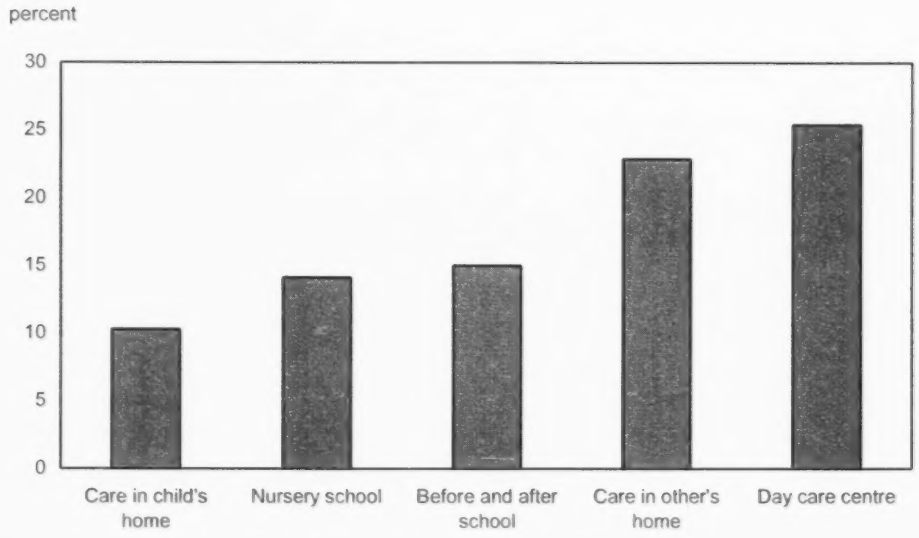
When selecting a child care arrangement, 91.2% of parents stated it was essential or important that the staff were able to address the special needs of the child and that the facility was physically accessible. In addition, 94.5% reported it was essential or important that the hours fit their schedule. This was followed by nearly nine in ten (87.3%) stating the importance of reasonable cost for the service.

Parents were satisfied with the type of childcare arrangements they were using. More than nine in ten (94.2%) reported satisfaction that ranged from somewhat to very satisfied. Furthermore, just over two-thirds (69.3%) of parents reported that their current childcare arrangement was the preferred method and would not change if another option was available.

Difficulties with childcare

While most parents were satisfied with the type of child care they currently had, more than one in five (21.5%) stated that childcare services or programs had refused to provide care for their child. In over one-quarter of (25.4%) these cases, daycare centres had refused child care. In addition, in more than one fifth (22.9%) of cases, caregivers in a home other than the child's had refused service (chart 8).

Chart 8
Percentage of parents that reported a program or service that refused to provide child care, Canada, 2006



Source: Statistics Canada, *Participation and Activity Limitation Survey, 2006*

Severity of the child's limitation had a significant effect on whether child care was refused or not. In particular, close to one third (31.7%) of children with severe to very severe disabilities were refused services.

Financial assistance for childcare

Just over one third (35.1%) of families were receiving financial assistance or subsidies for child care expenses. Severity of the child's disability had an impact on whether the parents were receiving financial assistance. Nearly three in ten (28.4%) parents with a child with a mild or moderate activity limitation received assistance, compared to the larger proportion of over four in ten (41.9%) for parents of children with more severe disabilities.

Transportation

Families may experience additional expenses in the process of arranging special transportation for their child. Often, accessible taxis or buses are required to accommodate the child's disability. Many of these services have costs associated with them and may contribute to financial burden on the family.

Nearly one third (29.7%) of parents stated having some out-of-pocket expenses for transportation for the child in the past 12 months. Eight in ten (79.9%) of parents reported expenses ranging from $1 up to $500. Parents of children with a more severe disability were twice as likely to report having out-of-pocket expenses for transportation (41.6%) than did parents of children with a mild to moderate disability (20.9%).

Conclusion

The results from the 2006 Participation and Activity Limitation Survey indicate that the impact of having a child with a disability can be felt in many aspects of family life.

A trend appeared while examining the relationship between the severity of the disability and the effect on a parent's life. For the majority of families, it was not the disability that posed the challenge; rather it was the severity of that disability. This trend was visible in many areas of the parent's lives.

Overall, the majority of parents of children with disabilities reported high levels of satisfaction with their health and lives in general. However, in comparison to parents of children who had mild to moderate disabilities, parents of children whose disabilities were severe to very severe were less likely to evaluate their own health and life satisfaction as good to excellent, and were more likely to indicate that they had high levels of stress. In addition, parents of children with severe to very severe disabilities were more likely to indicate that their child's disability had an impact on their employment, finances, leisure and personal time, and their ability to find help and childcare.

Although the degree to which parents were affected varied with the severity of a child's disability, the areas in which families were impacted were largely the same. In 2006, over three-quarters of parents reported feeling stress and one-quarter indicated that the stress was due to the child's disability. Many parents indicated that they felt that they needed more personal time and that they were not getting the help they required in caring for the child. Many parents felt that they should be doing more for their child.

The impact on employment varied, with some parents opting to reduce their hours of work or change their hours to accommodate the needs of the child. Others decided to turn down promotions or quit working. Of the parents that were affected, mothers made most of the adjustment in their employment.

Many families indicated that they had not experienced any financial or economic difficulty related to their child's condition within the previous 12 months. However, financial outcomes were influenced by the severity of the child's disability as families with children whose disabilities were severe to very severe were more likely to indicate that they had experienced financial strain. Households with children who had a disability were more likely to fall below the Low-Income Cut-Off than were households with a non-disabled child.

Of parents' currently married or living common law, the majority reported that the child's condition did not cause a strain on the relationship.

A large proportion of parents felt they needed more help in caring for their child. Many parents reported that they incurred out-of-pocket expenses for the help they needed and almost three quarters of parents indicated that extra help was too expensive and therefore went without.

While many families relied on help from family and friends, those who had the resources sought childcare from different sources. One of the main sources of care was before and after school care. The majority of parents reported that the addressing of the child's special needs by the facility was a priority.